CABINET FOR HEALTH SERVICES

Commission for Children with Special Health Care Needs

Health and Development Division

(Emergency Amendment)

911 KAR 2:120E. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: 20 USC 1471-1485, 34 CFR Part 303

STATUTORY AUTHORITY: 20 USC 1473, 34 CFR 303.322, KRS 194A.030(7), 194A.050, 200.650-676

NECESSITY, FUNCTION, AND CONFORMITY: The Cabinet for Health Services is directed by KRS 200.650 to 200.676 to administer [~~all~~] funds appropriated to implement provisions, to enter into contracts with service providers, and to promulgate administrative regulations. This administrative regulation establishes [~~sets forth~~] the provisions for evaluation and eligibility policies pertaining to First Steps, Kentucky's Early Intervention Program.

Section 1. Evaluation. (1) A child referred to the First Steps program shall be evaluated [~~Every child shall have an evaluation~~] to determine eligibility.

(2)(a) A determination of eligibility pursuant to Section 2 of this administrative regulation, assessments in the identified area of delay, in accordance with 911 KAR 2:130, and the initial IFSP team meeting [~~(a) A primary evaluation~~] shall occur within forty-five (45) calendar days after a Point of Entry receives an initial [~~receipt of the~~] referral; or

(b) If a determination of eligibility, assessments and initial IFSP team meeting [~~primary evaluation~~] does not occur within forty-five (45) calendar days due to illness of the child or a request by the parent, the delay circumstances shall be documented.

(c) If [~~When~~] a family is referred for a determination of eligibility [~~evaluation by the initial service coordinator~~] and the family is under court order or a social services directive to enroll their child in First Steps, the court or social service agency shall be informed within three (3) working days by the initial service coordinator, if the family refuses to participate in the determination of eligibility [~~evaluation~~].

(3) [~~(d)~~] Child records of evaluations transferred from an in-state or out-of-state tertiary or developmental evaluation center [~~centers~~] shall be reviewed by the initial service coordinator and shall be utilized for eligibility determination if [~~when~~]:

(a) [~~1.~~] The records meet First Steps evaluation time lines established in subsection (4)(a) of this Section; and

(b) [~~2.~~] The records contain the [~~all~~] developmental evaluation information established in subsection (10)(a) and (b) of this Section ~~required by First Steps to determine eligibility~~].

(4) [~~(2)~~] The primary level evaluation is the first level in the First Steps evaluation system that shall be utilized to determine eligibility, developmental status and recommendations for further assessment to determine program planning.[~~:~~]

(a) If there is a previous [~~The~~] primary level evaluation [~~is used when there are no existing evaluations~~] available, it shall be used to determine eligibility if [~~within the allowed time limits~~]:

1. For children under twelve (12) months of age, the evaluation was [~~evaluations~~

~~shall have been~~] performed within three (3) months prior to referral to First Steps; or

2. For children twelve (12) months to three (3) years of age, the evaluation was [~~evaluations shall have been~~] performed within six (6) months prior to referral to First Steps; and

3. There is no compelling additional information or new concerns that would render the previous evaluation no longer valid.

(b) If there is a previous primary level evaluation available that was performed within the timeframes established in subparagraphs 1. or 2. of this paragraph but there are new concerns that shall render the evaluation no longer valid, the Initial Service Coordinator shall request a new primary level evaluation.

(c) [~~If~~] Primary level evaluations shall provide evaluation in the [~~all~~] five (5) developmental areas identified in Section 2(1)(a)1. through 5. using norm referenced standardized instruments that provide a score in the total domain for the five (5) areas ;

(d) [~~(c)~~] The primary level evaluation shall be provided by a multidisciplinary team consisting of a physician or nurse practitioner and a primary evaluator approved by the cabinet;

(e) [~~(d)~~] A primary level evaluation shall [~~be multidisciplinary and shall minimally~~] include:

1. A medical component completed by a physician or a nurse practitioner that shall include [~~includes~~]:

a. A history and physical examination;

b. A hearing and vision screening; and

c. A child's medical evaluation that shall be current in accordance with the

EPSDT periodicity schedule incorporated by reference in 907 KAR 1:034. [~~according to the following:~~

~~(i) For children under twelve (12) months of age, the medical evaluation shall have been performed within three (3) months prior to referral to First Steps; and~~

~~(ii) For children twelve (12) months to three (3) years of age, the medical evaluation shall be performed within six (6) months prior to referral~~];

2. A developmental component completed by a cabinet approved [~~a qualified~~] primary level evaluator that utilizes norm referenced standardized instruments, [~~measures and~~] the results of which shall:

a. Include the recommendation of a determination of eligibility or possible referral for a record review; and

b. Interpreted to the family prior to the discussion established in subsection (5) of this Section [~~IFSP team meeting~~].

(f) A primary level evaluation shall not be performed if a child has an established risk diagnosis established in Section 2(1)(c) of this administrative regulation.

(5) Prior to the initial IFSP team meeting the Initial Service Coordinator shall:

(a) Contact the family and Primary Level Evaluator to discuss the child's eligibility in accordance with paragraph (d)2.b. of this subsection. If the child is determined eligible, the team shall:

1. Make appropriate arrangements to select a Primary Service Coordinator;

2. Arrange assessments in the areas found to be delayed in accordance with 911 KAR 2:130; and

3. Assist the family in selecting service providers in accordance with 911 KAR

2:110. If the child is receiving therapeutic services from a provider outside of the First Steps program, the service coordinator shall:

a. Invite the current provider to be a part of the IFSP team;

b. Request that the provider supply the team with his assessment and progress reports; and

c. Have the First Steps provider of the same discipline consult with the current provider; and

(b) If the child is determined not eligible, the team shall discuss available community resources, such as EPSDT, CCSHCN's Title V programs, and other third party payors.

(6) At the initial IFSP team meeting the IFSP team shall:

(a) Include the following members:

1. The parent of the child;

2. The Initial Service Coordinator;

3. The Primary Service Coordinator;

4. A provider who performed an assessment on the child;

5. A First Steps provider who shall provide therapeutic intervention;

(b) Verify the child's eligibility;

(c) Review the evaluation information identified in subsection (4) of this Section;

(d) Review the assessment reports in accordance with 911 KAR 2:130;

(e) Determine the family's outcomes, strategies and activities to meet those outcomes; and

(f) Determine the services the child shall receive in order for the family to learn

the strategies and activities identified on the IFSP. [~~(3) Verification of a child's eligibility for services shall be based upon the review by parents and professionals at the initial IFSP meeting;~~]

(7)(a) [~~(4)~~] Reevaluations shall be provided if the IFSP team determines [~~when~~] a child's eligibility warrants review [~~or a new condition is suspected or becomes apparent;~~

~~(a) The need for reevaluation is determined by the IFSP team;~~

~~(b) Reevaluations shall be obtained at the level of evaluation determined to be needed by the IFSP team~~].

(b) Primary level reevaluations shall not be used to:

1. Address concerns that are medical in nature; or

2. Provide periodic, ongoing follow-up services for post testing or testing for transition.

(c) Based on the result of the reevaluation, the IFSP team shall:

1. Continue with the same level of services; [~~or~~]

2. Continue with modified services; or

4. Transition [~~Graduate~~] the child from First Steps services because the child is developmentally age appropriate [~~; or~~

~~4. Continue eligibility with a tracking and maintenance approach and reevaluate in six (6) months~~].

(8) A review of the child's First Steps record shall be [~~(5) An intensive evaluation is~~] the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation. [~~:~~]

(a) Upon obtaining a written consent by the parent, a service coordinator shall send a child's record to the CCSHCN for a record review if [~~A child shall be referred for an intensive level evaluation when~~]:

1. A primary evaluator identifies a need for further developmental testing necessary to clarify a diagnosis to further define the child's developmental status in terms of a child's strengths and areas of need; [~~or~~]

2. A child does not [~~doesn't~~] meet eligibility guidelines at the primary level, but an IFSP team member and [~~a primary evaluator or~~] the family still have concerns that the child is developing atypically and a determination of eligibility based on professional judgment [~~judgement~~] is needed; or

3. The IFSP team requests an intensive level [~~team~~] evaluation for the purposes of obtaining a medical [~~a~~] diagnosis or to make specific program planning and evaluation recommendations for the individual child.

(b)1. If a service coordinator sends a child's record for a record review, the following shall be submitted to the Record Review Committee, Louisville CCSHCN office at 982 Eastern Parkway, Louisville, Kentucky, 40217:

a. A cover letter from the service coordinator or primary evaluator justifying the referral for a record review;

b. Primary level evaluation information specified in subsection (10) of this Section;

c. Available assessment reports required in 911 KAR 2:130;

d. Available IFSPs;

e. Most recent progress reports from the IFSP team members. Reports older

than three (3) months shall include an addendum reflecting current progress; and

f. If requesting a record review for a child who is receiving speech therapy, a hearing assessment performed within six (6) months of the request.

2. The service coordinator or primary evaluator requesting the record review shall attempt to procure and submit the following information, if available:

a. Birth records, if neonatal or perinatal complications occurred;

b. General pediatric records from the primary pediatrician;

c. Medical records from hospitalizations; and

d. Records from medical sub-specialty consultations, such as neurology, orthopedic, gastroenterology or ophthalmology.

(c)1. Upon receiving a referral, a team of CCSHCN professional staff shall conduct a record review.

2. After conducting the record review, CCSHCN staff shall:

a.(i) Determine that there are at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age;

(ii) Determine that further developmental testing, diagnostics or additional professional judgment are required in order to adequately ascertain the child's developmental needs; and

(iii) Refer the child for an intensive level evaluation, the third level in the First Steps evaluation system; or

b.(i) Determine that there are not at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age; and

(ii) Provide the IFSP team with recommendation for transition planning;

c. Determine that the child meets or does not meet the eligibility criteria established in Section 2(1) of this administrative regulation; or

d. Provide the IFSP team with recommendations for service planning.

[~~A record review shall be done by an intensive team at the request of the IFSP team whenever:~~

~~1. There is a question of eligibility;~~

~~2. Concern for a child's condition; or~~

~~3. Effectiveness of a child's program plan.~~]

(d) Upon request of the CCSHCN, a team approved by the CCSHCN and consisting of the following members shall perform an intensive level evaluation [[~~(c)~~] ~~shall be provided by an approved team consisting of~~]:

1. A board certified developmental pediatrician; [~~or~~]

2. A pediatrician who has experience in the area of early childhood development; [~~and~~]

3. A pediatric physiatrist; or

4. A pediatric neurologist; and

5. One (1) or more [~~qualified~~] developmental professionals identified in 911 KAR 2:150, Section 1.

(9) [~~(6)~~] Family rights shall [~~must~~] be respected and procedural safeguards followed in providing evaluation services:

(a) Written parental consent shall be obtained before conducting an evaluation or assessment by the evaluator or assessor respectively.

(b) If a parent or guardian refuses to allow a child to undergo a physical or

medical examination for eligibility because of religious beliefs:

1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong.

2. If a child is determined [~~With the presence of a professional judgement of developmental delay that determines the child~~] to be eligible, First Steps shall provide, at the parent's request, services that do not require, by statute, proper physical or medical evaluations.

3. The Initial Service Coordinator shall explain to the family that refusal due to religious beliefs may result in a denial of services which require a medical assessment on which to base treatment protocols.

(10) [~~(7)~~] A written report shall be completed upon completion of an [~~for every level of~~] evaluation [~~including record reviews~~].

(a) A record review report shall include the components specified in this paragraph that can be addressed without having the child or parent present for the evaluation. A report resulting from a primary level evaluation or an intensive level evaluation shall include the following components [~~The minimum components are~~]:

1. Date of evaluation;

2. Names of evaluators and those present during the evaluation, professional degree, and discipline;

3. The setting of the evaluation;

4. [~~2.~~] Name and telephone number of contact person;

5. [~~3.~~] Identifying information that includes the:

a. Child's CBIS identification number [~~Age~~];

b. Child's name and address;

c. Child's chronological age (and gestational age, if prematurely born) at the time of the evaluation;

d. Health of the child during the evaluation;

e. [~~b.~~] Date of birth;

f. [~~c.~~] Date of evaluation;

[~~d. Evaluator's affiliation, and professional degree;~~]

g. [~~e.~~] Referral source; and

h. [~~f.~~] Reason for referral or presenting problems.

6. [~~4.~~] Tests administered or evaluation procedures utilized and purpose of instrument. No one (1) method of evaluation shall be used, but a combination of tests and methods shall be used;

7. [~~5.~~] Test results and interpretation of strengths and needs of the child;

8. [~~6.~~] Test results reported in standard deviation or developmental quotient if [~~when such~~] instrumentation is required pursuant to subsection (4)(d)2. of this Section;

9. Factors that may have influenced test conclusions;

10. [~~7.~~] Eligibility;

11. [~~8.~~] Developmental status or diagnosis;

12. [~~9. Program plan~~] Recommendations regarding an area that may need further assessment;

13. Suggestions regarding how services may be provided in a natural

environment that address the child's holistic needs based on the evaluation;

14. Parent's assessment of the child's performance in comparison to abilities demonstrated by the child in more familiar circumstances;

15. [~~10.~~] A narrative description of the [~~all~~] five (5) areas of a child's developmental status;

16. Social history;

17. Progress reports, if any, on the submitted information; and

18. Documentation that results of the evaluation were discussed with the child's parent.

(b) The [~~full~~] report established in paragraph (a) of this subsection shall be written in clear, concise language that is easily understood by the family.

(c)1. The reports and notification of need for further evaluation shall be made available to the current IFSP team within fourteen 14 calendar [~~ten (10) working~~] days from the date the evaluator received the complete evaluation referral [~~was completed~~].

2. A copy of the report completed by an Intensive Level Evaluation site shall be provided to the Record Review Committee within fourteen (14) calendar days from the date the evaluator received the evaluation referral.

3. If it is not possible to provide the report and notification required in this paragraph by the established timeframe due to illness of the child or a request by the parent, the delay circumstances shall be documented.

[~~(8) child records of timely evaluations transferred from out of state tertiary centers or developmental evaluation centers may be utilized for eligibility determination;~~

~~(a) These records shall be reviewed for all required evaluation record~~

~~components by the POE services coordinator;]~~

~~(b) If information is unattainable, the child shall be evaluated for eligibility.~~]

Section 2. Eligibility. (1) A child shall be [~~Children who are~~] eligible for First Steps services if he is:

(a) Aged [~~include those who are ages~~] birth through two (2) years;[~~,and:~~]

(b) A resident of Kentucky at the time of referral and while receiving a service;

[~~(a)~~](c) Through the evaluation process [~~By using appropriate diagnostic instruments and procedures or professional judgment, are~~] determined to have fallen significantly behind developmental norms in the following skill areas:

1. Total cognitive development;

2. Total communication area through speech and language development, which shall include expressive and receptive;

3. Total physical development including vision and hearing;

4. Total social and emotional development; or

5. Total adaptive skills development; and

(d) [~~(b)~~] Is [~~Are~~] significantly behind in developmental norms as evidenced by the following criteria:

1.a. Two (2) standard deviations below the mean in one (1) skill area;

b.A [~~(~~]developmental quotient equivalent of seventy (70) [~~percent~~] or below); or

c. A standard score of seventy (70) or below; or

2. At least one and one-half (1 1/2) standard deviations below the mean in two (2) skill areas; or

3. If a norm referenced testing reveals a delay in one of the five (5) total areas of

development that does not meet eligibility criteria, a more in-depth standardized test in that area of development may be requested if the following is evident:

a. The primary level evaluator, service coordinator or the family has a concern or suspects that the child's delay may be greater than the testing revealed;

b. A more sensitive norm referenced test tool may reveal a standardized score which would meet eligibility criteria; and

c. There is one (1) area of development that is of concern;

(e) Is being cared for by a neo-natal follow-up program and its staff determine that the child meets the eligibility requirements established in paragraphs (a) through (d) or (f) of this subsection; or

(f) Meets the criteria established in KRS 200.654(10)(b) who has one of the following conditions diagnosed by a physician or Advanced Registered Nurse Practicioner (ARNP):

Aase-Smith syndrome	Alper's syndrome
Aase syndrome	Amelia
Acrocallosal syndrome	Angelman syndrome
Acrodysostosis	Aniridia
Acro-Fronto-Facio-Nasal Dysostosis	Anophthalmia/Microphthalmia
Adrenoleukodystrophy	Antley-Bixler syndrome
Agenesis of the Corpus Callosum	Apert syndrome
Agyria	Arachnoid cyst with neuro-developmental delay
Aicardi syndrome	
Alexander's Disease	Arhinencephaly

Arthrogryposis	Cataracts - Congenital
Ataxia	Caudal Dysplasia
Atelosteogenesis	Cerebro-Costo-Mandibular syndrome
Autism	Cerebellar Aplasia/Hypoplasia/Degeneration
Baller-Gerold syndrome	
Bannayan-Riley-Ruvalcaba syndrome	Cerebral Atrophy
Bardet-Biedl syndrome	Cerebral Palsy
Bartsocas-Papas syndrome	Cerebro-oculo-facial-skeletal syndrome
Beals syndrome (congenital contractural arachnodactyly)	CHARGE Association
	Chediak Higashi syndrome
Biotinidase Deficiency	Chondrodysplasia Punctata
Bixler syndrome	Christian syndrome
Blackfan-Diamond syndrome	Chromosome Abnormality a. unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX;XXXY; XXXXY
Bobble Head Doll syndrome	
Borjeson-Forssman-Lehmann syndrome	
Brachial Plexopathy	
Brancio-Oto-Renal (BOR) syndrome	
Campomelic Dysplasia	CNS Aneurysm with Neuro-Developmental Delay
Canavan Disease	
Carbohydrate Deficient Glycoprotein syndrome	CNS Tumor with Neuro Developmental Delay
Cardio-Facio-Cutaneous syndrome	Cockayne syndrome
Carpenter syndrome	Coffin Lowry syndrome

Coffin Siris sydrome	Donohue syndrome
Cohen syndrome	Down syndrome
Cone Dystrophy	Dubowitz syndrome
Congenital Cytomegalovirus	Dyggve Melchor-Clausen syndrome
Congenital Herpes	Dyssegmental Dysplasia
Congenital Rubella	Dystonia
Congenital Syphilis	EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome
Congenital Toxoplasmosis	
Cortical Blindness	Encephalocele
Costello syndrome	Encephalo-Cranio-Cutaneous syndrome
Cri du chat syndrome	Encephalomalacia
Cryptophthalmos	Exencephaly
Cutis Laxa	Facio-Auriculo-Radial dysplasia
Cytochrome-c Oxidase Deficiency	Facio-Cardio-Renal (Eastman-Bixler) syndrome
Dandy Walker syndrome	
DeBarsy syndrome	Familial Dysautonomia (Riley-Day syndrome)
DeBuquois syndrome	
Dejerine-Sottas syndrome	Fanconi Anemia
DeLange syndrome	Farber syndrome
DeSanctis-Cacchione syndrome	Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)
Diastrophic Dysplasia	
DiGeorge syndrome (22q11.2 deletion)	Femoral Hypoplasia
Distal Arthrogryrosis	Fetal Alcohol syndrome/Effects

Fetal Dyskinesia	Hemimegalencephaly
Fetal Hydantoin syndrome	Hemiplegia/Hemiparesis
Fetal Valproate syndrome	Hemorrhage-Intraventricular Grade III, IV
Fetal Varicella syndrome	Hereditary Sensory & Autonomic Neuropathy
FG syndrome	
Fibrochondrogenesis	Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)
Floating Harbor syndrome	
Fragile X syndrome	Herrmann syndrome
Fretman-Sheldon (Whistling Facies) syndrome	Heterotopias
	Holoprosencephaly (Aprosencephaly
Fryns syndrome	Holt-Oram syndrome
Fucosidosis	Homocystinuria
Glaucoma - Congenital	Hunter syndrome (MPSII)
Glutaric Aciduria Type I and II	Huntington Disease
Glycogen Storage Disease	Hurler syndrome (MPSI)
Goldberg-Shprintzen syndrome	Hyalanosis
Grebe syndrome	Hydranencephaly
Hallermann-Streiff syndrome	Hydrocephalus
Hays-Wells syndrome	Hyperpipecolic Acidema
Head Trauma with Neurological Sequelae/Developmental Delay	Hypomelanosis of ITO
	Hypophosphotasia-Infantile
Hearing Loss (Bilateral permanent sensorineural 30dB pure tone average)	Hypoxic Ischemic encephalopathy
	I-Cell (mucolpidosis II) Disease

Incontinentia Pigmenti	Lennox-Gastaut syndrome
Infantile spasms	Lenz Majewski syndrome
Ininencephaly	Lenz Microophthalmia syndrome
Isovaleric Acidemia	Levy-Hollister (LADD) syndrome
Jarcho-Levin syndrome	Lesch-Nyhan syndrome
Jervell syndrome	Leukodystrophy
Johanson-Blizzard syndrome	Lissencephaly
Joubert syndrome	Lowe syndrome
Kabuki syndrome	Lowry-Maclean syndrome
KBG syndrome	Maffucci syndrome
Kenny-Caffey syndrome	Mannosidosis
Klee Blattschadel	Maple Syrup Urine Disease
Klippel-Feil Sequence	Marden Walker syndrome
Landau-Kleffner syndrome	Marshall syndrome
Lange-Nielsen syndrome	Marshall-Smith syndrome
Langer Giedion syndrome	Maroteaux-Lamy syndrome (MPS VI)
Larsen syndrome	Maternal PKU Effects
Laurin-Sandrow syndrome	Megalencephaly
Leber's Amaurosis	MELAS
Legal blindness (bilateral visual acuity of 20/200 or worse corrected vision in better eye)	Meningocele (cervical)
	MERRF
	Metachromatic Leukodystrophy
Leigh Disease	Metatropic Dysplasia

Methylmalonic Acidemia	Neonatal Meningitis/Encephalitis
Microcephaly	Neuronal Ceroid Lipofuscinoses
Microtia-Bilateral	Neuronal Migration Disorder
Midas syndrome	Nonketotic Hyperglycinemia
Miller (postaxial acrofacial-Dysostosis) syndrome	Noonan syndrome
	Ocular Albinism
Miller-Dieker syndrome	Oculocerebrocutaneous syndrome
Mitochondrial Disorder	Oculo-Cutaneous Albinism
Moebius syndrome	Optic Atrophy
Morquio syndrome (MPS IV)	Optic Nerve Hypoplasia
Moya-Moya Disease	Oral-Facial-Digital syndrome Type I-VII
Mucolipidosis II, III	Osteogenesis Imperfecta Type III-IV
Multiple congenital anomalies (major organ birth defects)	Osteopetrosis (Autosomal Recessive)
	Oto-Palato-Digital yndrome Type I-II
Multiple Pterygium syndrome	Pachygyria
Muscular Dystrophy	Pallister Mosaic syndrome
Myasthenia Gravis - Congenital	Pallister-Hall syndrome
Myelocystocele	Pelizaeus-Merzbacher Disease
Myopathy - Congenital	Pendred's syndrome
Myotonic Dystrophy	Periventricular Leukomalacia
Nager (Acrofacial Dysostosis) syndrome	Pervasive Developmental Disorder
Nance Horan syndrome	Peters Anomaly
NARP	Phocomelia

Pierre Robin Sequence	Schinzel-Giedion syndrome
Poland Sequence	Schimmelpenning syndrome (Epidermal Nevus syndrome)
Polymicrogyria	Schizencephaly
Popliteal Pterygium syndrome	Schwartz-Jampel syndrome
Porencephaly	Seckel syndrome
Prader-Willi syndrome	Septo-Optic Dysplasia
Progeria	Shaken Baby syndrome
Propionic Acidema	Short syndrome
Proteus syndrome	Sialidosis
Pyruvate carboxylase Deficiency	Simpson-Golabi-Behmel syndrome
Pyruvate Dehydrogenase Deficiency	Sly syndrome (MPS VII)
Radial Aplasia/Hypoplasia	Smith-Fineman-Myers syndrome
Refsum Disease	Smith-Limitz-Opitz syndrome
Retinoblastoma	Smith-Magenis syndrome
Retinoic Acid Embryopathy	Sotos syndrome
Retinopathy of Prematurity Stages III, IV	Spina Bifida (Meningomyelocele)
Rett syndrome	Spinal Muscular Atrophy
Rickets	Spondyloepiphyseal Dysplasia Congenita
Rieger syndrome	Spondylometaphyseal Dysplasia
Roberts SC Phocomelia	Stroke
Robinow syndrome	Sturge-Weber syndrome
Rubinstein-Taybi syndrome	TAR (Thrombocytopenia-Absent Radii
Sanfilippo syndrome (MPS III)	

syndrome)	deletion)
Thanatophoric Dysplasia	Wildervanck syndrome
Tibial Aplasia (Hypoplasia)	Walker-Warburg syndrome
Toriello-Carey syndrome	Weaver syndrome
Townes-Brocks syndrome	Wiedemann-Rautenstrauch syndrome
Treacher-Collins syndrome	Williams syndrome
Trisomy 13	Winchester syndrome
Trisomy 18	Wolf Hirschhorn syndrome
Tuberous Sclerosis	Yunis-Varon syndrome
Urea Cycle Defect	Zellweger syndrome
Velocardiofacial syndrome (22q11.2	

[~~3. Children may be determined to be developmentally delayed by professional, clinical judgement in the event~~] If ~~standard deviation scores are inconclusive and evaluation reveals the child has significant atypical development or quality or pattern of development, or further diagnostic evaluation is needed to address concerns related to the five (5) areas of development. Professional judgement to determine a child to be developmentally delayed shall be obtained from an approved evaluator; or~~

~~(2) Those Children who are diagnosed with physical or mental conditions which have a high probability of resulting in developmental delay and the diagnosis has been specified by KRS 200.645(10) as an established risk condition. The developmental delay shall be within one (1) of the following categories:~~

~~(a) Chromosome abnormalities associated with developmental delay;~~

~~(b) Recognizable yndromes associated with developmental delay;~~

~~(c) Abnormality in central nervous system;~~

~~(d) Neurological or neuromuscular disorders associated with developmental delay;~~

~~(e) Symptomatic intrauterine infection or neonatal central nervous system infection;~~

~~(f) Sensory impairments that result in significant visual or hearing loss, or a combination of both, interfering with the ability to respond effectively to environmental stimuli;~~

~~(g) Metabolic disease having a high likelihood of being associated with developmental delay, even with treatment;~~

~~(h) Maternal teratogen exposure at a level known to have a high risk for developmental delay;~~

~~(i) Behavioral or emotional disorders associated with extreme excesses or deficits which inhibit function;~~

~~(j) Central nervous system malignancy or trauma resulting in developmental delay.~~]

[~~(3)~~] (2) If a child referred to the First Steps program was born at less than thirty-seven (37) weeks gestational age, the following shall be considered [~~Eligibility for a premature child shall consider~~]:

(a) The chronological age of infants and toddlers who are less than twenty-four (24) months old shall be corrected to account for premature birth. The evaluator shall ensure that the instrument being used allows for the adjustment for prematurity. If it does not, another instrument shall be used.[~~;~~]

(b) Correction for prematurity is not appropriate for children born prematurely whose chronological age is twenty-four (24) months or greater.

(c) Documentation of prematurity shall include a physician's [~~physician~~], or nurse practitioner's [~~practitioner,~~] written report of gestational age and a brief medical history.

(d) Evaluation reports on premature infants and toddlers shall include test scores calculated with the use of both corrected and chronological ages.

Section 3. The provisions of this administrative regulation shall be effective with services provided on or after January 1, 2003.